

Notes February 9th, 2021

Age- and Dementia-Friendly Winnemucca and Humboldt County

This was such a fantastic and informative meeting. Thanks to everyone.

If you missed April's presentation, join us tomorrow at noon:

Winnemucca Alzheimer's Support Group meeting February 10th at noon via Zoom:

Zoom Link: [Click Here](#) or go to <https://zoom.us/join>

Enter MEETING ID: 957 7699 7847

Then enter PASSCODE: 651855

Attendance:

April Hardenbol

Alicia Heiser

Alicia Cramer

Penny Huber

Patty Ellifritz

Jolina Adams

Heidi Slater

Rich Stone

Karen Betz

Gini Cunningham

Legal - 0

Communities of faith - 0

Government agencies - 3

Transportation services - 0

Banks/Financial planning - 0

Emergency planners/first responders - 0

Businesses - 2

Hospital and acute care - 0

Neighbors and community members - 4

Libraries - 0

Community-based support services - 3

Residential care - 0

Educators - 2

Other:

The 8 Sectors of AARP Age-Friendly Communities Outdoor Spaces; Buildings and Structures Transportation Housing Social Participation	The 5 Sectors of Dementia-Friendly Nevada Transportation Services Community-based Supports and Services Neighbors and Community Members Businesses Outdoor Spaces; Buildings and Structures
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Respect and Social Inclusion Civic Participation and Employment Communication and Information Community Support and Health Services	
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Introductions

I. Guest Speaker April Hardenbol – caregiver for her father

Gini – I heard April speak at a Nevada Alzheimer’s Advocacy meeting and was so impressed with her presentation and all that I learned that I invited her to join us today as well as at my support group meeting tomorrow, February 10th, at noon. Zoom information for this session is at the top of these notes.

April (from Gini’s notes and paraphrasing): My Dad is a Navy vet who retired and moved to Reno for a little while and then he decided to stay. 8 years later he is still here. I was working in Texas and have always been close to my Dad and I could tell something was not quite right. While others said, “Nothing’s Wrong”, I knew something was. He’d had a bout with vertigo so I hijacked the appointment with a neurologist and joined him. In 2015 he was diagnosed with Alzheimer’s disease. I returned to Texas and my job and then in 2016 Reno PD called. Dad had reported a stolen wallet, one that he had misplaced, and that was the turning point. My employer in Texas allowed me to work part-time, remotely while keeping my health insurance so I moved, thinking I could help him with grocery shopping and finances. I had no idea what I was getting in to.

There were collection calls as I sorted through notes and passwords. I found that Dad had \$35,000 in credit card debts. I took 3 years to get Dad dept free.

I established him with the Reno VA that offers amazing resources. The social worker there has been so helpful. Know that it takes work and lots of navigation, but help is available. Dad originally had 30% service coverage but after 1 year of work this was increased to 100% disability. I had been thinking in the long-term, “How will I take care of this?” and the VA provided the answer. I worry about the financial concerns of caregivers. What happens when they do not have or do not know about potential financial support? I blinked and time had flown by. Dad could not remember when to take pills, how to make a sandwich. He lived in an old, 2-story apartment and I lived in another apartment on the 3rd floor. We had to find a place that eliminated the stairs where we could both live.

At first I was relieved because I no longer had to drive to his place to help him. But then moving him in with me created a new set of challenges. He still doesn’t know where he is and often thinks is in the home where he grew up.

It was different for me, too. Now I can’t go out to dinner with a friend as I need respite care and have to decide if it is worth the \$75.

Heidi [Slater] and the Alzheimer’s Association have helped me so much. So has the Continuum. Going there was a challenge at first as Dad didn’t want to go to a “senior center with all of those old people.” He became combative. Now I disguise where we are going and he does better.

The first weeks that he lived me he was violent. He yelled, threw a coke can at me. I wondered if I could keep him living with me. I took him to the new VA memory care facility – for down the line – and he said, “Go to Hell!”

It was at this point that I sought Guardianship. Guardianship is hard – it’s like taking a parent to court. This was in April 2020 and proved easier as Dad was in front of a computer screen [covid] rather than having to drag him to court. I knew I was responsible for him, but now I had taken on legal responsibility. Legal versus Emotional.

In this time I realize that the needs of a parent, a caregiver, and covid do not align. I hit the “Pause” button on my own life.

I try to be thankful every day and that caring for a person I love, my Dad, is my #1 priority. I was working 2 jobs although now it is down to 1. While friends can binge-watch and stay in their pajamas all day, I cannot. I am not alone. I’m with family, but he is not my Dad. My Dad is a brilliant man. He was a cryptologist during Vietnam, deciphering Morse code and messages. I had to ban the news channels in our home so I would not have to answer, “What’s corona virus?” again and again. Now he watches the game channel. There are no questions.

For much of 2020, daycare was closed and respite didn’t want to come in our home. I reached out to an aunt in Massachusetts and despite covid, we flew east for a 6-week break. I felt so much better and was able to do a better job of caring for my Dad.

With Alzheimer’s disease, you hit an obstacle, jump through hoops, and wow! You hit another brick wall.”

Dad had become violent and so I took him to a psychiatrist who put him on medication to calm his mood bursts.

I breakdown when I think of fellow peer caregivers who think they are all alone.

Wondering how to pay for care and also take care of themselves. Accessing health insurance is important and there is a fear of losing a job and losing benefits. This puts a caregiver in an emotionally bad place.

Research and funding are critical to finding a cure, but in the meantime, we have to take care of caregivers by showing the smallest act of kindness. The waitperson who realizes, “This person has dementia; now I know why he can’t order for himself.”

[Small interruption while April checks on Dad with her phone app “Nanny” cam]

Patty – it is so important to know that you are not alone.

Maria – I worked as a public guardian and there are many who care, but others who just are tired of caregiving.

April – there are angels all along the way. My conversations with my social worker are so helpful. When Dad had a mini-stroke (TIA) and I asked the VA what do I do, they responded, “We are here to help.”

Caregivers have to ask, “How much of my life am I dedicating to caregiving?” with Alzheimer’s disease this can be a few years or it can be 20. There are caregivers who take the person to the ER, leave, and refuse to come back, waiting for the person to become a ward of the state.

Heidi: to get a social worker one can call the VA (if the individual is a veteran), the county, ADRC Care Connection, call Nevada 2-1-1, seek help from ADSD, chat with a local senior center.

Information from Heidi Slater of Alzheimer's Association on social workers:

Humboldt County access to aging services: Access to Health Care Network: 877-861-1893 OR call 2-1-1

The physical location of the aging resource center that serves Humboldt County is actually in Elko. Access To Health Care Network is the company that manages the resource center

Phone: 877-861-1893

<https://www.nevadaadrc.com/about-us/connect#elko-eureka-humboldt-lander-white-pine>
1071 Idaho Street | Elko, NV 89801

Thanks, April. We learned so much.

- II. **Sprint Triathlon date – September 18th, 2021. Standard set as 3rd Saturday of September. www.adf-winnemucca.com
Alicia Heiser will create a training guide that we will use as our June, July, and August *Sun* ads. Alicia says we don't want people to start training too soon as they may become tired and discourage and so quit before the event.**
- III. **Appreciation Wall –Photo op in coming up soon. Gini mentioned that the benches are parallel to the wall making it a little uninviting and some of the plaques are crooked. Alicia stated that if the benches are not bolted down they can be adjusted and that the adhesive to hold the plaques is tricky and must be held in place to avoid slippage.
(Thanks, Alicia!)
The new bench with shade and the table with shade have arrived. When we visit the Appreciation Wall as a group we can make some decision on placement. Patty stated that the Basque Club wants their bench to be placed by the balance beam.**
- IV. **Community Garden update - Alicia. There is work to be done, primarily because when the garden was created most of the topsoil was removed and so it is sitting on bedrock. This should not be a problem as the beds will have soil placed in them. The irrigation system is more of a concern
Maria who chatted with Jim M. thinks some weed pulling will get things rolling. He and Teresa Mavity will be our guest presenters in March.
Jim was concerned that the bench from ADF-Winnemucca had been removed. Gini had suggested moving it because it had never been paid for. The same is true of the bench at the Boys and Girls Club. The Club will order their own bench with their logo.**
- V. **Caregiver opportunity – a class and support: Anakaren Lamas**

As promised, I have information about a unique research opportunity for Alzheimer's disease primary family caregivers. This is an NIH-funded intervention focused on caregiver well-being that is being conducted by the University of California, San Francisco and Northwestern University.

The intervention, titled **Life Enhancing Activities for Family Caregivers (LEAF)**, includes six positive emotion skill-building sessions delivered either one-on-one via Zoom videoconferencing with a trained LEAF facilitator or via a self-guided platform online. Participants will be supplied with tablet computers, so caregivers can take part from anywhere in the USA. The program is recruiting 120 Alzheimer's caregivers nationwide and caregivers are invited to keep the tablet when they complete the study.

Participant commitment:

- (6) hour long positive emotion-based skill-building sessions, delivered over 6 weeks.
- Participants will be assigned to access the 6 sessions via a self-guided platform online or via Zoom videoconferencing with one of the trained LEAF facilitators.
- Nightly home practice and online emotion check-ins.
- A tablet will be provided by the study. Participants are invited to keep the tablet at the end of the study.

Eligibility Criteria:

- 18 or older
- Identify as the primary caregiver of someone with Alzheimer's Disease
- Have consistent access to a reliable Wi-Fi connection for your weekly sessions
- Speaks and reads English

Hand-out attached – please spread the word.

This same group has another project called PARK. Gini has signed up and will give a report on this next month.

VI. **April ended our meeting with 2 wonderful quotes:**

“Keep your humor.”

“Laughter is goodness.”

A special thanks to Penny Huber from South Lake Tahoe for joining us.

Next meetings:

March 9th

April 13th



Mobilizing Beliefs

Dementia Friendly Nevada is guided by a deep belief that each person living with dementia remains, and will always remain, a full human being and his or her rights as a citizen are, and shall always be, intact. To guide our dementia-friendly and inclusive efforts, we offer a set of **mobilizing beliefs**, which can help serve as a type of ethical roadmap for restoring and ensuring fundamental rights and opportunities to people living with dementia who have been disenfranchised by a prevalent view that discounts and diminishes their value and potential contributions to our communities and state.

1. People are **living** with dementia. In order to support each person in living with dementia, we must destigmatize dementia and see beyond the common tragedy narrative. People can live well with dementia when they are afforded with opportunities for meaning, purpose and growth.
2. People living with dementia are not their diagnosis. Person-first language should replace labels such as ‘dementia sufferer’ or ‘Alzheimer’s patient’. Such labels perpetuate an ‘us versus them’ mentality. In truth, *all* human beings are forgetful; some are just more forgetful than others.
3. If you know one person living with dementia, you only know one person living with dementia. Generalizations based on notions of ‘age’ or ‘stage’ are limiting and often wrong. Understanding the experience of living with dementia requires understanding each person as a unique human being.
4. People living with dementia are the genuine experts in the experience of dementia. Their perspectives, wishes and preferences should always be sought and respected in the decisions that affect their lives. Truly engaging each person living with dementia as a legitimate contributor to his or her own experience opens a world of possibilities.
5. People living with dementia can and do communicate and express themselves meaningfully across the entire continuum of the disease experience. It is

important that care partners and community members develop the ability to listen with more than their ears and to speak with more than their words.

6. Contrary to the increased use of the term, there is no such thing as “behavioral and psychosocial symptoms of dementia” (BPSDs). So-called

“behaviors” are actually a form of communication; communicating identity, preferences and/or unmet needs. Instead of pathologizing behaviors, care partners and professionals should seek to understand and validate personal expressions, actions and reactions.

7. Sometimes, what makes care partners feel safe and secure makes people living with dementia feel trapped and anxious, including locked environments.

8. “Redirection” is a code-word for distracting, manipulating or charming someone living with dementia into doing what *you* want them to do. Instead, care partners and community members should respond supportively and seek to understand the world from another person’s perspective.

9. Just as the Americans with Disabilities Act ensures ramps for people living with physical disabilities, it should also ensure that communities provide adaptations and supports (i.e., cognitive ramps) for people living with dementia and other cognitive disabilities.

10. Communities and service agencies need to offer affordable, accessible and proactive community-based supports and services. The more energy and resources devoted to community-based supports and services, the less need there is for expensive and reactive interventions and institutional care settings.

11. People living with dementia should never be segregated, like convicted criminals. Each citizen has the right to live freely and safely in the community of their choosing. Even in circumstances where a person requires additional support due to cognitive impairment, the living environments offered should be normalized, inclusive and not merely ‘homelike’ but an actual home, without restrictions or restraints on one’s freedom. There are many ways to guarantee safety besides locked doors.

12. Persons living with dementia should have access to affordable person- and relationship-centered residential care and support that nurtures each person’s well-being and upholds their right to autonomous decision making to the fullest extent possible. This requires an appropriate care partner to resident ratio.

13. Though most forms of dementia are degenerative, people living with dementia can continue to grow and thrive when care partners and organizations avoid the tendency to medicalize, sterilize and surveil all aspects of everyday life.

14. Supporting engagement, autonomy and partnerships with people living with dementia will promote improvements to their quality of life and well-being, and strengthen the social fabric of communities. Elders need communities and communities need elders.

While each of these mobilizing beliefs are represented in various ways by Dementia Friendly Nevada, the responsibility to ensure that all people living with dementia are respected and valued as active citizens and important members of our communities resides with all community members and leaders.